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Report of the Independent Expert on the enjoyment of human rights by persons with albinism

Note by the Secretariat

The Secretariat has the honour to transmit to the Human Rights Council the report of the Independent Expert on the enjoyment of human rights by persons with albinism pursuant to Council resolution 28/6. In her report, the Independent Expert explores matters concerning the enjoyment of the right to the highest attainable standard of health by persons with albinism. On the basis of information gathered from surveys, reports and country visits, she conceptualizes the multifaceted challenges in the field of health, including disabilities arising from visual impairment and the high number of fatalities caused by skin cancer in certain regions, the applicable norms and standards in international human rights law, the continuing challenges and best practices. In so doing, she discusses contextual factors, as well as exogenous elements, including health determinants. She highlights the important work being carried out by civil society and makes several recommendations centred on the call for more government ownership and initiative in this area.

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Report of the Independent Expert on the enjoyment of human rights by persons with albinism

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I. Introduction

1. The present report is submitted pursuant to resolution 28/6 of the Human Rights Council, in which the Council established the mandate of the Independent Expert on the enjoyment of human rights by persons with albinism.

2. In section II of the report, the Independent Expert provides an overview of the activities undertaken since March 2017, in particular regarding attacks, related human rights violations and discrimination against persons with albinism. In section III, she focuses on the right of persons with albinism to the highest attainable standard of health, particularly with regard to visual impairment and their high susceptibility to skin cancer and related ailments.

II. Activities of the Independent Expert

3. In 2017, the Independent Expert conducted country visits to the United Republic of Tanzania (A/HRC/37/57/Add.1) from 18 to 28 July 2017 and to Fiji from 27 November to 7 December 2017. The report of the mission to Fiji will be presented to the Human Rights Council in March 2019.

4. The report on the Independent Expert's visit to the United Republic of Tanzania contains details of the measures taken by both the Government and civil society to significantly decrease the number of reported attacks against persons with albinism. However, the Independent Expert stresses that progress remains extremely fragile, as the root causes of the attacks are still widespread in the country. During her visit to Fiji, the Independent Expert focused on the measures taken to address and mainstream the right of persons with albinism to the highest standards of health, to combat discrimination and to ensure their full access to education.

A. Regional Action Plan on Albinism in Africa (2017–2021)

5. The Regional Action Plan on Albinism in Africa (2017–2021) to address attacks and related human rights violations against persons with albinism has now been finalized (see A/HRC/37/57/Add.3). The Plan was developed by the Independent Expert through consultations with representatives from the United Nations, the African Union, Governments, organizations of persons with albinism and other civil society organizations. It is based on various recommendations by international bodies and mechanisms, and sets out 15 specific, concrete and time-bound measures in key areas, such as public education and awareness-raising, systematic data collection, research on the root causes of violence, the use of legal and policy frameworks to deter harmful practices related to witchcraft and trafficking in body parts, and measures to fight impunity and to ensure support for victims.

6. The Regional Action Plan was endorsed by the African Commission on Human and Peoples' Rights during its 60th ordinary session in May 2017.[1] In addition to endorsing the Plan, the Commission urged all States parties to the African Charter on Human and Peoples' Rights to take all the measures necessary for its adoption and implementation and invited the relevant organs and bodies of the African Union to give due regard to adapting and implementing the Plan.

7. In that context, the Independent Expert convened[2] a regional meeting in Pretoria in November 2017 with representatives from international organizations and civil society, including organizations of persons with albinism, to design an implementation strategy for the Plan. That strategy is currently being finalized and will be launched in 2018.

[1] Resolution 373 (LX) 2017.

[2] With the University of Pretoria and the Open Society Foundations.

B. Witchcraft-related harmful practices

8. In previous reports (A/HRC/34/59 and A/71/255), the Independent Expert showed how interrelated factors, including witchcraft-related harmful practices, contributed to ongoing outbreaks of attacks and discrimination against persons with albinism.

9. To further the debate, the Independent Expert organized, in Geneva in September 2017, the first-ever systematic and in-depth workshop[3] on witchcraft and human rights. The two-day workshop brought together United Nations experts, academics and members of civil society to discuss the violence associated with such beliefs and practices and their impact, particularly on groups in vulnerable situations, including persons with albinism.

10. Workshop participants addressed the various manifestations of witchcraft, its scope, the difficulties associated with its definition and its links to harmful practices, as well as ritual attacks and killings. In addition, victims of witchcraft-related harmful practices shared their experiences. The workshop was concluded with an identification of best practices, recommendations and suggestions for the way forward (A/HRC/37/57/Add.2).

C. Other activities

11. In addition, the Independent Expert participated in numerous public engagements, including interventions in a multiplicity of local and international media events, conferences, campaigns, consultations and expert meetings, which allowed her to increase awareness among a diverse and extensive audience, provide input, share information and promote good practices with regard to the enjoyment of human rights by persons with albinism.

III. The right to health of persons with albinism

A. Introduction

12. Persons with albinism are entitled to the highest attainable standard of health without discrimination of any kind. Under international human rights law, the content and scope of the right to health are defined by international standards and jurisprudence. Considering the evolutionary nature of those standards, the right to health of persons with albinism requires contextualization and the factoring-in of exogenous issues. That is particularly important because persons with albinism are victims of multiple and intersecting discrimination, which hinders the enjoyment of their right to the highest attainable standard of health.

13. The present report is based on research conducted and information collected by the Independent Expert through country visits, academic research, questionnaires sent to member States, organizations serving persons with albinism and other non-governmental organizations.[4]

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[3] With the University of Lancaster, the Witchcraft and Human Rights Information Network, the Special Representative of the Secretary-General on Violence against Children, the Special Rapporteur on violence against women, its causes and consequences, and the Special Rapporteur on extrajudicial, summary or arbitrary executions.

[4] Member States include Cuba, Honduras, Kuwait and Slovenia. Contributions were submitted by the following organizations of persons with albinism: the Albino Network Association of Nigeria; Association Ivoirienne pour la Promotion des Femmes Albinos; Association pour la Promotion des Albinos au Cameroun; Connexion Worldwide, Benin; Mwanza Albino Society, United Republic of Tanzania; Organization of Persons with Albinism in Rwanda; Portail des Droits des Personnes Handicapées en Afrique de l'Ouest, Mali; Rwanda Albinism Society; the Source of the Nile Union of Persons with Albinism, Uganda; and Stukie Motsa Foundation, Swaziland. Information was received from the non-governmental organization Kilimanjaro Sunscreen (KiliSun) and the Kilimanjaro Sunscreen Production Unit, United Republic of Tanzania.

B. Condition of albinism

14. Throughout the world, people are born with albinism, which is a relatively rare, non-contagious, genetically inherited condition that affects people regardless of ethnicity or gender. In order for a person to be affected by albinism, both parents must carry the gene. In such cases, there is a 25 per cent chance at each pregnancy that a child will be born with albinism. The condition is characterized by a significant deficit in the production of melanin, which results in the partial or complete absence of pigment in any part or all of the skin, hair and eyes.

15. There are different types of albinism. The most common and visible type is oculocutaneous albinism, which affects all of the skin, hair and eyes. Within this type, there are various subtypes, which may reflect varying degrees of melanin pigment deficiency.[4] The main subtypes of oculocutaneous albinism are tyrosinase negative albinism and tyrosinase positive albinism. In tyrosinase negative albinism, there is little or no production of melanin; it is often characterized by white hair and opaque or transparent irises. In tyrosinase positive albinism, which is the more prevalent subtype, particularly in African countries, some melanin is produced; it is characterized by yellow-blonde or sandy-coloured hair and grey to light brown irises. Less common forms of albinism include ocular albinism, which affects the eyes alone, and Hermansky-Pudlak syndrome, which is albinism with bleeding and bowel (colitis) disorders, and lung diseases.

16. In addition to significantly affecting appearance, albinism often results in two congenital permanent health conditions: visual impairments to varying degrees and high susceptibility to ultraviolet-induced skin damage, in particular skin cancer.

C. Exogenous health determinants

17. The enjoyment of the right to health by persons with albinism, in particular regarding visual impairment and the susceptibility of the skin to solar damage and cancer, requires consideration of exogenous determinants of health. Visual impairment relates to a condition of the body and leads to disability insofar as the manner in which "environment and society respond to that impairment".[5] As recognized in preamble to the Convention on the Rights of Persons with Disabilities, disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinder their full and effective participation in society on an equal basis with others. Similarly, the Committee on Economic, Social and Cultural Rights specifies that the right to health embraces a wide range of socioeconomic factors that promote conditions under which people can lead a healthy life. Those extend to the underlying determinants of health, such as food and nutrition, housing, access to safe and potable water and adequate sanitation, safe and healthy working conditions, and a healthy environment.[6] For instance, in the Bhatti Tribe of Pakistan, in which about 5 per cent of its members are persons with albinism, a study found that "most of them are economically poor and cannot afford to buy sun protection medicines and clothing required for this condition".[8] Likewise, in Nigeria, the barriers to eye care faced by persons with albinism include poor awareness, non-availability

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[4] See, for example, Octaldine R. McBride, "Oculocutaneous albinism: an African perspective", *British and Irish Orthoptic Journal*, vol. 11 (2014), pp. 3–8, at p. 3: "Melanin is a photo-protective protein whose role in the skin is to absorb ultraviolet (UV) light and prevent damage; without melanin the skin is more prone to sunburn and skin cancer. Lack of melanin results in a triad of signs — pale skin, light hair and pale iris colour — but the consequence of [oculocutaneous albinism] is impaired visual acuity (VA)."

[5] Theresia Degener, "Disability in a human rights context", *Laws*, vol. 5, No. 3 (2016).

[6] See general comment No. 14 (2000) on the right to the highest attainable standard of health, para. 4.

[8] Azam Jah Samdani and Bahram Khan Khoso, "A unique albino village of Bhatti tribe in rural Sindh, Pakistan, with oculocutaneous albinism manifestations: an epidemiological study", *Iranian Journal of Dermatology* (2009).

of such care, financial constraints and limited accessibility, notably regarding transportation due to the uneven spatial distribution of services.[9]

18. In addition to the socioeconomic and environmental factors, a range of other exogenous determinants greatly, and often negatively, affect the enjoyment of the right to health by persons with albinism. Those factors include myths, discrimination and stigmatization, which are often conveyed and reinforced through popular culture, such as folklore, media and film, and exacerbated by a widespread lack of awareness about albinism, including among health professionals. Any consideration of such exogenous determinants requires "a reorientation in dealing with albinism — away from just medical intervention to treating it as a social construct requiring a holistic approach".[10]

19. In sub-Saharan Africa, it has been widely documented that myths and misbeliefs surrounding persons with albinism have led to witchcraft-related harmful practices, involving the use of their body parts obtained through brutal attacks and mutilations.[11] In that region, the psychological impact of stigmatization and fear of being attacked greatly affect the health of persons with albinism. For instance, in the United Republic of Tanzania, persons with albinism — victims or not — often exhibit a high level of anxiety, including hypervigilance scanning, which is often a response to a ubiquitous fear in all environments.

20. Moreover, it is reported that persons with albinism — particularly when there is a strong visible contrast between their appearance and that of the general population — are rejected, shunned and excluded from their community, owing to the myths surrounding the condition and related stigmatization.

21. Climate is also a significant risk factor. Regions of high sun exposure represent a particular threat to persons with albinism, such as in the Sahel, equatorial countries, the South Pacific and South America.

D. International normative framework

22. Article 12 of the International Covenant on Economic, Social and Cultural Rights provides the most comprehensive normative framework on the right to the highest attainable standard of health. It is buttressed by specific provisions in other international[12] and regional[13] human rights instruments.

The right to health

23. Pursuant to that article, States parties should take all appropriate measures to ensure access for persons with albinism to gender-sensitive health services, including health-related rehabilitation. In particular, States parties shall provide tailored health services for the condition of albinism, and ensure that such health services are made available as close

[9] N.N. Udeh and others, "Oculocutaneous albinism: identifying and overcoming barriers to vision care in a Nigerian population", *Journal of Community Health*, vol. 39, No. 3 (2014), pp. 508–513.

[10] R.J. Gaigher, P.M. Lund and E. Makuya, "A sociological study of children with albinism at a special school in the Limpopo province", *Curationis* (2002).

[11] A/HRC/34/59.

[12] The right to health is also recognized in the following international legal instruments: International Convention on the Elimination of All Forms of Racial Discrimination, art. 5 (e) (iv); Convention on the Elimination of All Forms of Discrimination against Women, arts. 11 (1) (f), 12 and 14 (2) (b); Convention on the Rights of the Child, art. 24; International Convention on the Protection of the Rights of All Migrant Workers and Members of Their Families, arts. 28, 43 (e) and 45 (c); and Convention on the Rights of Persons with Disabilities, art. 25.

[13] The right to health is also recognized in several regional instruments, such as the African Charter on Human and Peoples' Rights, the Additional Protocol to the American Convention on Human Rights in the Area of Economic, Social and Cultural Rights, known as the Protocol of San Salvador (1988) and the European Social Charter (1961, revised in 1996). The American Convention on Human Rights (1969) and the Convention for the Protection of Human Rights and Fundamental Freedoms (1950) contain provisions related to health, such as the right to life, the prohibition on torture and other cruel, inhuman or degrading treatment or punishment, and the right to family and private life.

as possible to local communities where persons with albinism live. Furthermore, States parties shall require health professionals to provide care of the same quality to persons with albinism as is available to others; prohibit discrimination against persons with albinism in the provision of health services; and prevent discriminatory denial of health care or health services on the basis of disability or colour.

24. The right to health also includes four interrelated elements: availability, accessibility, acceptability and quality. In addition, it entails ensuring access to an adequate system of health protection without discrimination, the right to prevention and treatment of illnesses, the right to access essential medicines, the provision of health-related education and information, and the participation of those concerned in health-related decision-making.[14]

The rights of persons with disabilities

25. Persons with albinism are entitled to the same rights and standards enjoyed by persons with disabilities, owing to the lack of sufficient melanin in their eyes and skin, which results in sensitivity to bright light, visual impairment, susceptibility to skin cancer and various associated barriers in society. It is essential to reassert that human rights are inalienable, regardless of health or disability status. In accordance with the Convention on the Rights of Persons with Disabilities, States have a duty to provide reasonable accommodation in order to ensure de facto equality of persons with disabilities.[15] The Convention also recognizes the right to the enjoyment of the highest attainable standard of health, without discrimination on the basis of disability.[16]

Equality and non-discrimination

26. Persons with albinism also face discrimination on the basis of colour, which leads to significant barriers to the enjoyment of the right to health. In that regard, the Committee on the Elimination of Racial Discrimination recognizes that persons with albinism suffer from racial discrimination, as it is discrimination based on colour, one of the prohibited grounds of racial discrimination listed in article 1 of the International Convention on the Elimination of All Forms of Racial Discrimination.[17]

27. Discrimination against persons with albinism on the basis of colour manifests itself in a variety of forms. They include harmful practices,[18] and physical attacks and mutilation motivated by witchcraft-related beliefs and practices, which often lead to death, as reported in 28 countries in sub-Saharan Africa. In that region, pre-existing conditions include a widespread belief in witchcraft and, in particular, ambiguity between the practice of witchdoctors and practice of traditional medicine.[19]

28. In that regard, the International Convention on the Elimination of All Forms of Racial Discrimination lays down the obligations of States parties to prohibit and eliminate racial discrimination in all its forms and to guarantee the right of everyone, without distinction as to race, colour, or national or ethnic origin, to public health, medical care, social security and social services.[20] Therefore, under the Convention, persons affected by racial discrimination, including persons with albinism, are entitled to benefit from special measures by States parties until de facto equality is guaranteed.[21]

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[14] Committee on Economic, Social and Cultural Rights, general comment No. 14.

[15] Arts. 2 and 5.

[16] Art. 25.

[17] See CERD/C/ZAF/CO/4-8, paras. 20–21.

[18] Joint general recommendation No. 31 of the Committee on the Elimination of Discrimination against Women/general comment No. 18 of the Committee on the Rights of the Child (2014) on harmful practices.

[19] See A/HRC/34/59, para. 56.

[20] Art. 5.

[21] General recommendation No. 32 (2009) on the meaning and scope of special measures in the Convention.

Intersecting and multiple discrimination

29. Persons with albinism are discriminated against on the basis of intersecting grounds, largely based on disability and colour. According to reports and direct observation, discrimination based on colour exacerbates the consequences of disability, in particular when there is high degree of contrast between the colouring of persons with albinism and that of the dominant population. According to Patricia Lund, in sub-Saharan Africa for example, "this appearance, so strikingly different from normally pigmented family members and the rest of the black community, results in problems of acceptance and social integration for those affected."[22]

30. In other words, discrimination against persons with albinism should be understood as a specific situation stemming from the intersection of both disability and colour. Also, multiple discrimination affects subgroups and individuals among people with albinism. For instance, persons with albinism who are women and those affected by HIV/AIDS face aggravated discrimination.[23]

31. Therefore, an understanding of the challenges and identification of promising practices to ensure the right of persons with albinism to the highest attainable standard of physical and mental health require a holistic approach. Such an approach should also address the contextual and exogenous determinants that underpin specific situations at the intersection of both disability and colour, which manifest themselves with different degrees of severity according to the specific context.

IV. Issues and challenges

32. The most pressing health issue faced by persons with albinism is skin cancer. That fact has been firmly established on the basis of several studies and consultations with civil society organizations, particularly those working with persons with albinism. In addition to skin cancer, other urgent health issues include visual impairment and mental health.

33. Persons with albinism are also subject to other health problems not linked to the condition of albinism. Those include common conditions and illnesses to which they have become more vulnerable, owing to poverty and pre-existing discrimination and neglect of albinism in the health and social services system, in general. Organizations of persons with albinism reported specific health problems, such as malnutrition and dehydration, tropical diseases, such as malaria and typhoid fever, infectious diseases, HIV/AIDS, cholera and chronic non-communicable diseases.

34. At present, the enjoyment of the right to the highest standard of mental and physical health by persons with albinism is far from a reality. As a consequence, health issues and intersecting discrimination in the context of exogenous factors have an impact on the enjoyment of other human rights, such as the right to life and socioeconomic rights.

A. Impact of health issues on the right to life

35. The most serious health issue affecting the enjoyment of the right to life by persons with albinism is their susceptibility to skin cancer. In addition, the discrimination and stigmatization arising from skin colour leads to immediate life-threatening crimes in contexts in which witchcraft-related misbeliefs and harmful practices are widespread.

High susceptibility to skin cancer

36. It has been indicated in several reports that most persons with albinism in sub-Saharan Africa die from skin cancer between the ages of 30 and 40 years.[24] In the case of

[22] P.M. Lund, "Oculocutaneous albinism in southern Africa: population structure, health and genetic care", *Annals of Human Biology*, vol. 32, No. 2 (2005), pp. 168–173, at pp. 168–169.

[23] Submission of the Association Ivoirienne pour la Promotion des Femmes Albinos.

[24] Submissions of Connexion Worldwide and the Source of the Nile Union of Persons with Albinism.

the United Republic of Tanzania, which has been a prime beneficiary of multiple interventions on the issue, and consequently accounts for a significant amount of data on the matter, it has been reported that half the population of persons with albinism "will develop advanced skin cancer between 20 and 30 years of age, with less than 2 per cent of albino children in Tanzania living to be 40 years of age".[25] It was also indicated in an earlier study that "chronic skin damage was found in all those with albinism by 12 months of age".[26] In those circumstances, the prospects of having limited or no access to preventive measures and treatments for skin cancer would inevitably lead to premature although preventable death — all of this despite the fact that the susceptibility of the skin of a person with albinism to cancer and other solar damage has been known for at least half century.[27] The risk is exacerbated in sunny climates closer to the equator, but it is still a permanent and universal risk for persons with albinism throughout the world. In Cuba, where persons with albinism enjoy free access to the health system, a small number of cases of skin cancer are reported.[28]

37. In poor countries, "sunscreens are prohibitively expensive, leading to a focus on sun avoidance and protection from an early age".[29] At schools in sunny climates, sun exposure may also differ between boys and girls as they tend to have different leisure activities and wear different clothes. The Association Ivoirienne pour la Promotion des Femmes Albinos reports that women may be more vulnerable to sun exposure due to the type of clothes they wear and their daily activities, including childcare. In their study of children with albinism in a specialized school in South Africa, Patricia Lund and Julie Taylor observed that boys play football outdoors, while girls prefer activities in shaded areas. In that regard, data collected by the only cancer institute in the United Republic of Tanzania shows that men and boys are significantly overrepresented at their clinic. Thus, a gender perspective is required in devising responses to the susceptibility of persons with albinism to skin cancer. However, it is essential to remember that sunburn and similar damage could still occur in the shade. That is why adequate protective clothes are key in sun avoidance and protection.

38. Outdoor working conditions aggravate the risks and the prevalence of skin cancer among persons with albinism, particularly in rural areas.[30] Limited employment opportunities and vocational training condemn most to outdoor income-generating activities under extended sun exposure. Furthermore, a lack of health facilities and health programmes, including screening and treatment, directly contribute to the high mortality rate of persons with albinism owing to skin cancer.

39. For those who already have skin cancer, treatment is often not available. In Benin, for instance, Connexion Worldwide reports that they are not aware of any specialized centre for screening and treatment of skin cancer. In Uganda, the Source of the Nile Union of Persons with Albinism reports that the only radiotherapy machine in the country has been broken for a long period. Furthermore, the risk of skin cancer is higher when persons with albinism seek help too late after the appearance of the first symptoms, or fail to follow preventive measures or complete their treatment regimen.[31] Factors accounting for those issues include the lack of priority accorded to prevention measures given the need for immediate survival, self-isolation to avoid further stigmatization, fear of attack, lack of information and lack of financial means to cover the cost of transport to health centres and other costs.

[25] Geraldine R. McBride, "Oculocutaneous albinism: an African perspective", p. 11.

[26] Patricia M. Lund and Julie S. Taylor, "Lack of adequate sun protection for children with oculocutaneous albinism in South Africa", *BMC Public Health*, vol. 8 (2008).

[27] A.N. Okoro, "Albinism in Nigeria: A clinical and social study", *British Journal of Dermatology*, vol. 93, No. 5 (1975), pp. 485–492.

[28] Submission of Cuba.

[29] P.M. Lund, "Oculocutaneous albinism in southern Africa".

[30] Submission of Connexion Worldwide.

[31] Geraldine R. McBride, "Oculocutaneous albinism: an African perspective".

Attacks, rape, mutilation, infanticide and trafficking of body parts

40. Discrimination and stigmatization against persons with albinism, owing to myths and misbeliefs, lead to several human rights violations. Foremost is the violation of the right to life, which often takes the form of attacks, mutilations, trafficking of body parts and infanticide. For instance, in Benin, there are reports that infanticide has been carried out based on the misbelief that children with albinism cause misfortune.[32] Similarly, in Zimbabwe, it is reported that, "traditionally, children with albinism were associated with witchcraft and bad omens and were killed at birth".[33] Instances of infanticide have also been reported in Swaziland.[34] Furthermore, there is also the prevalent "death myth", which holds that persons with albinism do not die but simply disappear.

41. In some regions, it has been reported that persons with albinism are the subject of positive misbeliefs, such as being considered gods or quasi-deities, as in southern Benin[35] or in the Kuna Lands in Panama.[36] In those cases, the misbeliefs do not generate a direct threat. However, their apparently benign origin is not to be automatically looked upon as favourable since they are still misbeliefs, ignorant of the condition of albinism. Such misbeliefs are also dangerous because they associate the value, dignity and, ultimately, the human rights of persons with albinism with a subjective interpretation, which could change over time.

42. The life expectancy of persons with albinism, particularly children and women with albinism, is also put at risk by harmful practices based on misbelief and witchcraft. A number of countries in sub-Saharan Africa continue to be affected by the ritual defilement and rape of girls and women with albinism because of the belief that their body parts have magic or medicinal qualities. This situation has been caused by the myth that having sexual intercourse with a woman with albinism can cure HIV/AIDS. As a result, persons with albinism, in particular women and children, are more susceptible to HIV infections and face further stigmatization and self-isolation. Persons with albinism who are HIV-positive may not seek treatment for fear of being easily identified. All those factors constitute a multifaceted barrier affecting the right to live in dignity and the life expectancy of persons with albinism, in particular, women and children with albinism.

II. Impact of health issues on socioeconomic rights

43. The absence of reasonable accommodation for visual impairment and health care regarding susceptibility to cancer hamper the enjoyment of the right to health, as well as other socioeconomic rights. Access to education and employment by persons with albinism are particularly undermined.

Right to education

44. Visual impairment and the associated lack of reasonable accommodation represent a serious barrier to keeping children with albinism in school. In addition to stigmatization and bullying, visual impairment partly accounts for low school attendance. The high susceptibility of skin to cancer and other conditions also act as barriers in accessing education when reasonable accommodation is not provided. For instance, participants at the first Fiji Albinism Awareness Symposium, held in 2015, observed that vision aids and sunscreen were not generally available for children in village schools.

45. Often, the absence of reasonable accommodation at school is due to the lack of awareness about albinism among communities and teachers. For instance, the belief that

[32] Submission of Connexion Worldwide.

[33] J.S. Taylor and P.M. Lund, "Experiences of a feasibility study of children with albinism in Zimbabwe: a discussion paper", *International Journal of Nursing Studies*, vol. 45, No. 8 (2007), p. 1250.

[34] Submission of Stakie Motsa Foundation, Swaziland.

[35] Submission of Connexion Worldwide.

[36] P. Acambrun, "Oculocutaneous albinism: clinical, historical and anthropological aspects", *Archives de pédiatrie: organe officiel de la Société française de pédiatrie*, vol. 5, No. 8 (August 1998), pp. 906–907.

children with albinism develop blindness is widespread across the medical and educational sectors and is resulting in children being taught Braille when they do not require it. In some countries those with albinism are registered as "legally blind" or "blind", although this does not mean they have no vision."

Right to work

40. The overall health situation of persons with albinism described above, along with discrimination and stigmatization, represent a barrier to favourable conditions of work, in particular regarding safe and healthy working conditions.[74] For instance, in a study on members of the Lunga community with albinism living in a remote area of Zimbabwe, it was highlighted that sensitive skin and photophobia prohibited them from participating in agricultural and fishing activities and that very few other opportunities for work existed.[75]

41. Furthermore, the appearance of skin cancer lesions on persons with albinism, often confused with albinism itself due to the lack of awareness, leads to even more stigmatization and exposes persons with albinism to further discrimination, particularly when seeking employment.[76] In Pakistan, many persons with albinism "attribute their cosmetic disability as one of the reasons for their joblessness".[77] Similarly, in Nigeria "social discrimination, often associated with albinism, constitutes a major obstacle to building of social relationships and finding/maintaining an occupation among persons with albinism".[78] Reported examples of discrimination and stigmatization in India include refusing to provide work placements and having to sign a declaration to release a college from its duty to provide placements to students.[79] Similarly, in Spain, it was reported that persons with albinism had been discriminated against based on their physical appearance, in particular in employment that required direct contact with clients. Potential employers considered that their appearance could have a negative impact on their business.[80]

Women and girls' rights

42. As pointed out above, women and children, in particular girls, suffer multiple discrimination owing to targeted rape by persons with HFS/ASPS. Consequently, survivors of sexual violence can experience increased health complications, such as post-traumatic stress disorder, pregnancy and sexually transmitted infections.[81]

C. Psychosocial impact and mental health

43. Mental health has been identified by persons with albinism as one of their major health issues.[82] The issue is global, as the psychological and mental "stress" of stigmatization is reported worldwide. The need for psychological and rehabilitative support should not be underestimated, not only for those that have survived attacks and mutilations, but also for all persons with albinism who experience fear, bullying, stigmatization, lack of

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[74] P. Lynch, P. Lund and B. Masuku, "Identifying strategies to enhance the educational inclusion of visually impaired children with albinism in Malawi", *International Journal of Educational Development*, vol. 30 (2010), pp. 216–224.

[75] International Covenant on Economic, Social and Cultural Rights, art. 7 (b).

[76] Patricia M. Lund and others, "Underestimated albinism in an isolated Lunga community in Zimbabwe", *Journal of Medical Genetics*, vol. 34, No. 4 (1997), pp. 333–338.

[77] See A/HRC/31/63, para. 39.

[78] Alam Sab Samadani and Bahram Khan Khoso, "A unique albino village of Bhatti tribe in rural Sindh, Pakistan, with oculocutaneous albinism manifestations: an epidemiological study".

[79] S.N. Ukoh and others, "Oculocutaneous albinism: identifying and overcoming barriers to vision care in a Nigerian population", p. 7.2.

[80] Information from persons with albinism.

[81] Asociación de Ayuda a Personas con Albinismo, Spain.

[82] Under the Same Sun, "Survey on albinism and social discrimination", 2017.

[83] Information received from persons with albinism.

social life, rejection by families and isolation, leading to depression and mental illness.[49] In Kuwait, for instance, persons with albinism face psychological and social challenges, although they benefit from health care and are not the subject of superstitious beliefs.[50]

50. In Brazil, a study found that the quality of life of persons with albinism is not only affected by poor vision and skin lesions, but also by social stigmatization. Similarly, in South Africa, research highlights that "it is often the negative response to albinism by others that is more hurtful, especially to children, than having to cope with the condition itself".[51] In Côte d'Ivoire, persons with albinism bear testament to the fact that discrimination and exclusion lead to the loss of self-esteem, isolation, sleep disorders and attempted suicide.[52]

51. In Abuja State in Nigeria, a study found that elderly people with albinism experienced several psychosocial problems, such as harassment, abandonment, neglect, withdrawal, isolation, rejection, divorce, labelling, stigmatization, suspicion, frustration and limited opportunities.[53]

52. The oppressiveness of isolation has been observed in Pakistan, where persons with albinism felt different, abnormal, abandoned and helpless, as they were excluded from health care and services.[54] In Zimbabwe, "The Zimbabwe Albino Society insists ... that many families keep children with albinism hidden at home, not sending them to school because of the associated stigma and bullying from both children and adults. Consequently, self-esteem is extremely low in children with albinism."[55]

53. Another negative impact on mental health is caused by the aggravated discrimination of those subject to the stigmatization triggered by the appearance of skin cancer lesions on persons with albinism, which, in several countries, are mistakenly perceived to be a natural part of albinism.[56] Indeed, the "skin, being the largest organ in the body, carries immense psychological significance".[57] Therefore, "disfiguring skin disorders ... may negatively distort a patient's body image".[58]

54. Furthermore, such stigmatization may have far-reaching psychopathological consequences, such as self-exclusion from services, alienation and social withdrawal, loss of identity, poor self-image, depression and anxiety.[59] With regard to self-exclusion, this has been observed even in institutions of higher education. A study on the beliefs and stereotypes concerning albinism at a South African university found that "students with albinism tend[ed] to exclude themselves from the rest of the student community to avoid discrimination and stereotypes around their condition".[60]

55. Social isolation strategies often have negative psychological consequences, such as depression and anxiety. Such an impact also derives from perceived stigmatization, which "relates to feelings of shame and the oppressive fear of enacted stigma and predicament, the

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[49] Submission of Fórum das Lutas dos Povos Hipoalbinos e Amigos do Albinismo - Forpah Albinismo Worldwide and the Rwanda Albinism Society.

[50] Submission of Kuwait.

[51] P.M. Lund, "Understanding albinism in southern Africa", pp. 175, 177.

[52] Submission of Association Ivoirienne pour la Promotion des Enfants Albinos.

[53] Ayonma Babatunde Adekanye, Omosanya Folorunsho Ogini and Alao Moses Taiwo, "Health and psychosocial complaints of elderly albinos in Ondo State, Nigeria", Indian Journal of Gerontology, vol. 24, No. 1 (2010), pp. 364–381.

[54] Asim Ali Nawabi and Bahram Khan Khattak, "A unique albino village of Bkaito tribe in rural South, Pakistan, with multicentauric albinism manifestations: an epidemiological study".

[55] T.L. Taylor and P.M. Lund, "Experiences of a knowbility study of children with albinism in Zimbabwe: a discussion paper", p. 1270.

[56] See A/HRC/11/4/Add.3, para. 39.

[57] I. Sukwianta M. Iskandar and others, "Quality of life of subjects with leprosy and albinism", International Journal of Psychiatry, Disease Journal, vol. 8, No. 8 (2010), pp. 1–6.

[58] Ibid., abstract.

[59] Kolobelo Dhanti, Nomsimbeko Jula and Eleanor Ross, "Being black in a white skin: beliefs and stereotypes around albinism at a South African university", African Journal of Disability, vol. 1, No. 1 (2012).

[60] Ibid., p. 6.

stigmatized persons to behaviours that avoid exposing their condition to protect themselves from experiencing discrimination".[47]

56. The emergence and manifestation of stigmatization "represent the intersection of psychological processes with the cultural construction of the condition".[48] In the case of persons with albinism, Carolyn Palmer observed that myths, stereotypes and self-perception did have an impact on self-esteem.[49] Regarding the impact of culture, research conducted in Malawi found that children with albinism and their families experienced "a range of cultural and social events that impact strongly and negatively on their mental and social well-being".[50]

57. Similarly, in Zimbabwe, it was reported that "in a society where albinism is [accepted] in myth and superstition, regarded as a curse and contagion, affected families lack a supportive environment and often felt isolated and helpless".[51] Thus, families are also subject to the impact of stigmatization, apart from cases in which parents and family reject children with albinism.

D. Health of displaced persons

58. When displaced, persons with albinism face particular risks, such as a heightened risk of violence, particularly violence related to witchcraft practices, exploitation and abuse, including sexual and gender-based violence, as well as high levels of stigmatization. In addition, persons with albinism, as persons with disabilities, also face numerous barriers in access to humanitarian assistance, education, employment, health care and other services, and are often excluded from decision-making processes and leadership opportunities.

59. In certain countries, persons with albinism have fled and continue to flee their homes in the wake of attacks. In the United Republic of Tanzania, as a temporary protection measure, certain schools and centres have been designated as centres of refuge for persons with albinism.[52] Most of these are government-run and a few others are private. The designated schools were originally designed for a limited number of people with particular disabilities and special needs. However, as an emergency measure in response to attacks, some of them have had to accept an unsustainable number of persons with albinism who are seeking protection. In addition, such shelters can no longer be considered temporary, and have ceased to be considered as exceptional emergency measures. Other less formalized camps of refuge, such as police stations, have been reported in other countries, such as Burundi. However, up-to-date information on those centres is sparse.[53]

60. In an assessment of the situation in the United Republic of Tanzania carried out in 2015 by the African Committee of Experts on the Rights and Welfare of the Child, the Committee noted "the deteriorating health conditions of the children".[54] They further elaborated that children at one of the main centres, Buhangija, were suffering from various forms of health-related challenges. For instance, many could not afford simple remedies,

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[47] Ibid., p. 8.

[48] Ibid., p. 1.

[49] Carolyn Palmer, "Myths, stereotypes and self-perception: the impact of albinism on self-esteem" British Journal of Visual Impairment, vol. 25, No. 1 (2007), pp. 144–154.

[50] P. Lynch, P. Lund and R. Mkandi, "Identifying strategies to enhance the educational inclusion of visually impaired children with albinism in Malawi", p. 6.

[51] J.S. Taylor and P.M. Lund, "Experiences of a household study of children with albinism in Zimbabwe: a discussion paper", p. 1291.

[52] See http://internet.ohchr.org/Countries/ZA/Shared%20Documents/TZA/INT_CRC_NGO_TZA_18032_E.pdf.

[53] International Federation of Red Cross and Red Crescent Societies, "Through albino eyes: the plight of albino people in Africa evokes Red Cross response". Available at http://reliefweb.int/sites/reliefweb.int/files/resources/E49262187152387949C1257673004A2F4-Full_Report.pdf.

[54] [illegible] of children with albinism in temporary holding shelters", (2016), p. 7.

such as sunscreen, that would protect them from the elevated risk of developing skin cancer. A medical screening camp found out that 80 per cent of the children had sunburns and signs of pre-cancer. Most of the children with albinism had visual impairments, fungus, severe wounds on their skin and suffered from complicated health problems accompanied by high fever. It was also indicated that malaria was a major challenge.[57] The dispensary and sickbay on site was found to be too small and ill-equipped to attend to those issues, such that the health of the children was severely endangered.

61. In 2017, the Independent Expert visited some of those centres, including Buhangija, and noted some improvements. However, she also pointed out that more needed to be done, including to ensure implementation of plans to increase living accommodation, the provision of adequate meals and the safe reintegration of residents back into their families and communities.[58]

F. Health and sustainable development

62. Human rights are increasingly recognized as essential to sustainable development and are the main aim of the Sustainable Development Goals.[59] The goals refer to the core content of the right to health, namely ensuring healthy lives and promoting well-being for all at all ages. To that end, specific targets are listed, including those particularly relevant to the situation of persons with albinism. They include universal access to health-care services, access to quality essential health-care services, financial risk protection, and access to affordable essential medicines and vaccines.[60]

63. Furthermore, a key principle of the Sustainable Development Goals is to leave no one behind. This is repeated seven times throughout the 2030 Agenda and applies to sectional goals, including on health. Persons with albinism have historically been left behind in terms of health services. A quintessential example is the absence of sunscreen on the list of essential medicines of many countries that have sunny climates and therefore the lack of access to such products.

64. That lack of access to a fundamental health product for persons with albinism leads to loss of life. Some may view such a loss as a mere drop in the economic bucket, since persons with albinism are a minority quantitatively speaking. Yet, the loss of one life is one too many and such a view would not be in accordance with the unconditional nature of fundamental human rights, particularly the right to life, or the prohibition of discrimination in implementing States' obligations deriving from the right to health. Finally, such a view is at odds with the Sustainable Development Goals, which are aimed at reaching everyone, beginning initially with those furthest behind.

65. The Sustainable Development Goals provide a framework for action and underpin the priority accorded to health initiatives by the Independent Expert, including through the Regional Action Plan on Albinism in Africa (2017–2021), which she developed with multiple stakeholders in sub-Saharan Africa.

F. Health financing

66. Persons with albinism are particularly vulnerable in low-income countries, in which they are often poor and public health services are limited.[61] In such countries, Governments often face many challenges in guaranteeing the progressive realization of the right to health, in accordance with international human rights obligations. At the same time, it is reported that many persons with albinism face the likelihood of early death from skin cancer — a condition that is preventable with basic and affordable interventions. Moreover, the

[57] Ibid., p. 8.
[58] See www.ohchr.org/EN/NewsEvents/Pages/DisplayNews.aspx?NewsID=21915&LangID=E.
[59] See www.ohchr.org/EN/Issues/MDG/Pages/The2030Agenda.aspx.
[60] See targets 3.7 and 3.8 of the Sustainable Development Goals.
[61] See A/72/169, para. 19.

majority of persons with albinism do not have access to, or are unable to afford, the necessary protective devices, whether for skin cancer prevention or to accommodate visual impairment.[72]

67. In this context and in accordance with international human rights law, States have the immediate obligation to ensure, at the very least, minimum essential levels of the right to health for persons with albinism,[73] to take steps towards the realization of that right[74] and to refrain from discrimination against persons with albinism.[75] In that regard, States should prioritize health resources for the most poor and marginalized, even in the face of barriers,[76] and adopt or facilitate low-cost measures that would have an immediate impact on the health of persons with albinism, such as including sunscreen in the list of essential drugs and providing sun protection clothing and devices.

68. States should resort to international cooperation and external funding when resources are scarce. They should support the work of organizations and agencies developing and implementing programmes on the right to health of persons with albinism. In that regard, the Committee on Economic, Social and Cultural Rights recognizes that non-State actors — in addition to States, which are the primary duty-bearers — should also bear responsibility for the right to health. States parties should therefore provide an environment that facilitates the discharge of those responsibilities.[77]

69. Local governments can also play a pivotal role, as reported by the Source of the Nile Union of Persons with Albinism in Uganda, in which "some local governments in the Busoga subregion have started to include small budget allowances to support persons with albinism, and some of this allowance may be used to purchase sunscreen, although the allowances are not sufficient to meet total needs".[78] The complementary actions of national Governments, local governments, civil society and international organizations could fill the affordability gap.[79]

V. Best practices

70. There are several best practices worth highlighting as effective initiatives in guaranteeing the right to health of persons with albinism. They include innovative initiatives with minimal cost implications, which promise potential for scaling-up and replication.

A. Country strategies

The Fiji Albinism Project

71. The Fiji Albinism Project is an initiative — initially undertaken by civil society that later involved government institutions — which developed a national response to the needs of persons with albinism. The project emerged from the first Fiji Albinism Workshop, held at the Fiji School for the Blind in 2014. The project's steering committee was formed within the Ministry of Health. The project subsequently organized the first Fiji Albinism Awareness Symposium in 2015.

72. Several barriers affecting the lives of persons with albinism in Fiji were identified during the symposium, including: lack of accurate demographic national data on persons with albinism; limited understanding of albinism in the health and education sectors;

[72] Such as in Mwanza, United Republic of Tanzania, as reported by the Mwanza Albino Society.
[73] Committee on Economic, Social and Cultural Rights, general comment No. 14, para. 43.
[74] Ibid., para. 30.
[75] Ibid., para. 43.
[76] A/72/169, para. 19.
[77] General comment No. 14, para. 42.
[78] Ibid.

limited multisectoral communication, and lack of access to services to support persons with albinism and lack of designated funding.[70]

73. As a result, the symposium fostered the implementation of measures to address the health issues of persons with albinism, including awareness at community level, notably to overcome the cultural issues preventing the wearing of hats and sunglasses, as well as through a campaign addressing provincial service officers. Recommendations included increasing awareness at the educational level, granting permission to wear protective clothing and ensuring the application of sunscreens in school settings. Reasonable accommodation was also recommended, including allowing children with albinism to sit at the front of the class with their backs to the windows, mobility around the classroom to improve vision and access to documents with large print.

74. At the national and regional levels, there were recommendations to increase access to health services across the country, through monthly albinism clinics and low-vision clinics. As regards affordability and accessibility, there were recommendations made at the Symposium to investigate the possibility of producing sunscreen locally and distributing it through clinics and schools. In the meantime, as part of the project, monthly skin and eye clinics are organized in Suva.[71] Similarly, there was a suggestion to provide low cost sunglasses through the Fiji Society for the Blind.

75. Finally, the project is governed through multisectoral coordination among the ministries responsible for health, education and women's issues. Modalities of work include the sharing of information, measures to enhance individual care and the appointment of dedicated staff. While the Ministry of Health provides skin and eye clinics, civil society provides free sunscreens and eyeglasses and the Ministry of Education disseminates information on albinism. Today, the main challenges of the project are funding and data collection.[72]

Kenya

76. In 2015, the Government commenced a programme for the purchase and distribution of sunscreen for people with albinism through the National Council for Persons with Disabilities and the Kenya Medical Supplies Authority.[73] In 2016, the Albinism Society of Kenya reported that more than 1,000 persons with albinism had been provided with prescription glasses and other optical devices.[74]

77. High-level stakeholders and leaders in the sector, such as Grace Mumbi Ngugi, Isaac Mwaura and other persons with albinism, convinced the Government to allocate funds for the provision of sunscreen in hospitals, as well as free protective clothing for persons with albinism. As a result, a programme on albinism, with a dedicated officer, was established at the National Council for Persons with Disabilities. Its initial goal was to register persons with albinism so as to plan the allocation of public resources.

78. The programme has been granted significant funding to deliver support to persons with albinism, including the provision of free sunscreen in district hospitals. However, it has been reported that challenges persist, particularly as regards accessibility and the affordability of services. For example, persons with albinism often live far away from district hospitals and free sunscreen is not available to them locally. In addition, it was reported that screening and treatment for skin cancer were not free of charge.[75]

[70] Fiji Albinism Project, "Summarised report" (2015).
[71] Charlene Lawson, "Albinism project", *Fiji Times Online*, 10 August 2016.
[72] Vishaal Kumar, "Albinism project faces big hurdles", *Fiji Times Online*, 15 June 2017.
[73] Under the Same Sun, "Kenyans with albinism and racial discrimination".
[74] See www.albinismsocietyofkenya.org.
[75] Diana Wanguai, "For people with albinism living in Africa, Kenya offers a haven of hope", *Nest* (Kenya), 10 October 2017.

Nigeria

79. In 2012, the Government of Nigeria, under the auspices of its Ministry of Education, adopted a national policy on albinism. The policy outlines the main health challenges faced by persons with albinism, including recommendations on the prevention and treatment of skin cancer.[55] The policy is holistic and covers several areas of work, including the promotion of self-esteem and a feeling of belonging, along with access to health and the promotion of free ophthalmological and dermatological services.

80. To that end, the policy establishes a target, to be achieved by 2020, of a 50 per cent improvement in accessing qualitative and affordable health and social services by persons with albinism. The interventions outlined in the policy will provide basic information and medical services for the prevention of visio-dermal health issues related to albinism; provide counselling and psychosocial services for persons with albinism by health systems stakeholders in public and private sectors; secure free, accessible qualitative treatment and rehabilitation of persons with albinism with skin cancer, sunburn and low vision.

81. The Ministry of Health, in partnership with the National Hospital in Abuja and the Albino Foundation, coordinate a project on free skin cancer treatment, which provides treatments that have a direct impact on avoiding premature deaths. According to the Albino Foundation, free medical treatment has been provided to over 4,000 persons with albinism who have skin cancer.[56] Today, the main challenges of the project are inadequate integration or mainstreaming in the health sector, funding and access to treatment, as the travel costs to Abuja remain prohibitive for most and subsidies by the Albino Foundation in this regard are limited.

United Republic of Tanzania and Malawi

82. In the United Republic of Tanzania and Malawi, the mobile clinics specifically attending to persons with albinism who live in non-urban centres have had a highly positive impact on skin cancer prevention and treatment, as well as reasonable accommodation for visual impairment.

83. In the United Republic of Tanzania, the Regional Dermatology Training Centre at the Kilimanjaro Christian Medical Centre has developed a comprehensive care programme for persons with albinism. The programme includes the registration and periodical health inspection of persons with albinism in different regions of the country; the provision of free dermatological services; education and awareness-raising on the importance of sun protection; and distribution of sun protection materials. In conjunction with Kilimanjaro Sunscreen (KiliSun) and Standing Voice, it covers 10 regions and reaches 2,000 persons with albinism.

84. Furthermore, the programme produces the locally made sunscreen, Kilimanjaro Sun Care or KiliSun, at the Kilimanjaro Sunscreen Production Unit. The unit produces and ensures a free supply of KiliSun, promotes the use of local resources and seeks to avoid reliance on external donations of commercial sun protection products.

85. This production of sunscreen responds to the realities and needs of persons with albinism, following a bottom-up approach. It offers a sun protection factor of at least 30 and protection against ultraviolet A and B radiation. The unit, in collaboration with health workers, community dermatologists and civil society, including the Tanzania Albinism Society and Standing Voice, ensure the quality of distribution, including assessment and education on the use of sunscreen.[57]

86. Moreover, in 2018, the Association of Persons with Albinism in Malawi will launch its first sunscreen pilot production in nine districts, in anticipation of the launch of a full-scale production unit in 2019 or 2020. This initiative is coordinated with the Government, United Nations agencies and KiliSun, and represents direct follow-up to the

[55] National policy on Albinism

[56] See albinofoundation.org

[57] Information received from KiliSun

recommendations of the Independent Expert, which were based on her visit to the country in 2016.

B. Other responses

Technological responses

87. There are specialized institutions and organizations that provide information on technological responses to the challenges posed by albinism, particularly visual aids and sun protection devices. That is important, because such devices, separately or together, may constitute a part of reasonable accommodation for each person with albinism. For instance, the National Organization for Albinism and Hypopigmentation provides regularly updated technical information on low-vision aids, including magnifiers, microscopes and telescopes, non-optical devices and strategies to improve one's vision. Similarly, the National Library of Medicine in the United States of America provides online medical information on albinism, including advice on genetic testing to identify the type of albinism and management of its signs and symptoms, particularly visual impairment and skin protection.

88. In Kuwait, technological services and approaches are applied in all hospitals to ensure complete diagnosis, including physical examinations, descriptions of changes in pigmentation, thorough eye examinations and genetic testing.[89]

Access to surgery and more specialized treatment

89. The type of surgery required for treating visual impairment may include strabismus surgery for either functional (improved peripheral fusion) or cosmetic procedures. Skin cancer treatment, including where there is a slightly enhanced risk of cutaneous melanoma, is not specific to albinism and includes cryogenic treatment, radiotherapy and chemotherapy.[90]

Early intervention measures: registration, counselling and training of nurses and medical staff, particularly in more remote areas

90. Registering persons with albinism at birth represents an important first response to address their health condition. Firstly, it provides the opportunity to inform and counsel the mother and the family about albinism and measures regarding skin protection and managing visual impairment as the child grows. Early information and care increase the prospect of the highest attainable standard of health of persons with albinism. However, records must have adequate safeguards to ensure the right to privacy and to prevent misuse of data for attacks, discrimination or other illicit acts.

91. Many studies confirm the need for awareness-raising and training of nurses and medical staff on albinism, particularly in remote areas. In this regard, good practices have been documented in South Africa in the clinical genetic outreach programme. That programme, which began in 1990, operates as a form of early intervention in the following manner: senior nurses at large rural hospitals, trained in medical genetics, form a network of professionals who identify babies with common genetic disorders at birth and offer immediate support and counselling.[91]

92. Counselling for mothers is essential in overcoming ignorance and misbeliefs about albinism and encouraging acceptance of their children. It also provides advice on the care necessary to prevent skin cancer. Counselling mothers can also prevent infanticide by demystifying the condition of albinism. In that regard, training on albinism for midwives and traditional birth attendants should be prioritized.[92] In addition to counselling, early intervention kits should be made available. For instance, the Kuwait Medical Genetic

[89] Submission of Kuwait.
[90] United States of America, Department of Health and Human Services, National Institutes of Health.
[91] P.M. Lund, "Oculocutaneous albinism in southern Africa", p. 170.
[92] Submission of the Source of the Nile Union of Persons with Albinism.

Centre provides parents with instructions and advice on precautions to help children learn self-care practices.[92]

Reaching circles of persons affected

93. A 2006 epidemiological study on albinism in sub-Saharan Africa, based on a World Health Organization pilot survey, investigated the situation of people with albinism in Africa, estimated that there were tens of thousands of people living with albinism in Africa and called for increased awareness and public health interventions to respond adequately to the medical, psychological and social needs of people with albinism. It recommended that, based on the estimates available and the severity of social issues faced by persons with albinism and their families, there should be a public health response to increase attention on this group of people.[93]

94. It is important to note that the above-mentioned study was conducted in advance of, and therefore without reference to, the violent attacks on persons with albinism, which were first reported internationally in about 2006. It is safe to say that its recommendation to extend support to all those directly affected by albinism has become even more compelling in the light of those attacks, as reports sent to the Independent Expert indicate that family members have also been affected by the attacks, both directly and indirectly. In recognition of the situation, the United Nations Voluntary Fund for Victims of Torture has provided funding to civil society to provide medical, psychological and social assistance support to persons with albinism who are attacked, together with their families.

95. Civil society organizations, such as Standing Voice and Under the Same Sun in the United Republic of Tanzania, are also trying to meet the need to assist family members of persons with albinism by running women's groups across the country. These groups consist of women with albinism and mothers of children with albinism. Various civil society groups globally have also reported doing outreach for the family members of persons with albinism in their ordinary course of work. However, these acts are only a drop in the bucket, as they are often ad hoc and not systemized, and therefore have limited reach.

VI. Conclusion and recommendations

96. **The main health issues faced by persons with albinism, namely visual impairment, high susceptibility to skin cancer and misbeliefs about the condition of albinism, have been known for more than half a century. Today, responses to those issues are mainly led by the tireless work of nascent organizations of persons with albinism and other civil society organizations, and are supported by research in this area. Nevertheless, those measures still need to be mainstreamed in health policies and strategies worldwide.**

97. **Accordingly, the Independent Expert recommends that Member States, particularly those in which there are records of attacks and in which the issue has been left out of mainstream health policies:**

General measures

(a) **Address health-related aspects of albinism as a public health concern;**

(b) **Ensure the adoption of special measures on persons with albinism in policies governing health and disabilities, as well as the training curricula of health-related professions.**

[92] Submission of Kuwait.

[93] Esther S. Hong, Hajo Zeeb and Michael H. Repacholi, "Albinism in Africa as a public health issue", *BMC Public Health*, vol. 6 (2006). Available at www.ncbi.nlm.nih.gov/pmc/articles/PMC1584235.

98. In this regard, the Independent Expert also recommends that member States:

(a) Include specific services for persons with albinism in existing health centres;

(b) Provide guidance for health professionals on the care needed by persons with albinism and ensure that the training of health workers, including ophthalmologists, dermatologists and nurses, includes topics on the condition of albinism and protective measures;

(c) Ensure that albinism is included in early intervention programmes on health, including dissemination of detailed health-care information and advice;

(d) Develop specific, concrete and time-bound national action plans on albinism;

(e) Ensure the prompt provision of medical and psychological support to the victims of attacks and their families;

(f) Ensure that the right to the highest attainable standard of health is exercised without discrimination of any kind, in particular against persons with albinism;

(g) Adopt special measures, if necessary, to guarantee equal access to health care for persons with albinism. Such measures should be based on statistical data and supported by adequate funding;

(h) Gather data systematically on persons with albinism, including when collecting data on health or disabilities, and by inserting a specific question on albinism in questionnaires when conducting population censuses;

(i) Adopt public health policies to address issues affecting persons with albinism, ensuring their full participation in the process of elaborating such policies and in awareness-raising action on such policies;

(j) Ensure that measures regarding the right to health of persons with albinism are the responsibility of the institution in charge of the issue, such as the ministry responsible for health;

(k) Ensure that the institution in charge of the issue, such as the ministry of health, carries out its mission in coordination with other relevant institutions, such as those in charge of disabilities, education, labour and social protection, as well as those with responsibility for women and children's rights.

99. Concerning skin cancer and visual impairment, the Independent Expert recommends that member States:

(a) Include sunscreen on the list of essential medicines without further delay;

(b) Ensure the availability, accessibility, affordability and quality of treatment for skin cancer without discrimination. Such treatment should include curative measures, as well as cosmetic treatment to restore or improve appearance to avoid further discrimination based on appearance;

(c) Deliver accessible and culturally appropriate rehabilitation programmes, particularly concerning skin cancer and visual impairment;

(d) Support or initiate the production and distribution of locally produced sunscreen, such as KiliSun. Distribution should include health education on the use of such a product;

(e) Support best practices, such as mobile clinics where they exist or initiate such measures;

(f) Ensure that specific measures for persons with albinism are integrated into disability-related programmes, including the distribution of vision devices as a means of reasonable accommodation;

(g) **Facilitate the importation of glasses and gadgets as a measure of reasonable accommodation, for example, by removing taxes and administrative costs associated with the importation of these goods.**

100. **With regard to exogenous conditions affecting the enjoyment of the right to the highest standard of physical and mental health, the Independent Expert reiterates her previous recommendations that member States, particularly those in which there are records of attacks:**

(a) **Conduct in-depth research on the root causes of attacks against persons with albinism, including on harmful practices related to witchcraft;**

(b) **Develop and implement long-lasting awareness-raising campaigns, as they are critical in addressing the harmful practices and rampant myths affecting the enjoyment of human rights by persons with albinism;**

(c) **Review and adapt legal frameworks, as needed, to ensure that they encompass all aspects of the attacks against persons with albinism, including with regard to the trafficking of body parts;**

(d) **Regulate the practice of traditional medicine, including through mechanisms such as Government-led licensing and monitoring regimes in both urban and rural areas, and establish adequate standards for traditional medicine;**

(e) **Ensure that social services are accessible to persons with albinism without discrimination and with reasonable accommodation, in particular in a manner that does not subject them to further stigmatization or require them to be exposed to the sun in order to receive support from social services;**

(f) **Cooperate with civil society organizations that provide support to persons with albinism and their families.**

101. **The Independent Expert recommends that civil society and Governments should, in the course of their work and in collaboration:**

(a) **Continue to conduct quality research to shape public policy and effectively implement sun protection strategies;**

(b) **Support prevalence and epidemiological studies as a basis for developing effective measures;**

(c) **Publish data acquired in the course of their work to inform collaborative work and develop policies and adequate measures;**

(d) **Continue to raise awareness to:**

(i) **Include specific information on albinism and, in particular, susceptibility to skin cancer in training for health professionals;**

(ii) **Ensure that there is no barrier to the recognition of persons with albinism as persons with disability;**

(iii) **Use international albinism awareness day as an opportunity to inform the general public about albinism and, whenever appropriate, engage in media campaigns to this effect.**

102. **The Independent Expert recommends that the World Health Organization, in response to recommendations made in the epidemiological study on albinism, pursue or facilitate government action to ensure that albinism is taken up as a public health concern, particularly where there are attacks and/or where there has been historical neglect to the detriment of the enjoyment of human rights by persons with albinism.**

103. **The Independent Expert recommends that the international community, including international organizations:**

(a) **Support efforts for the realization of the right to health of persons with albinism, such as the scaling-up of best practices identified in the present report, and by ensuring its insertion into existing health projects;**

(b) **Support epidemiological studies on albinism in order to gather the data necessary to develop public health policies;**

(c) **Ensure that, in particular in regions affected by attacks, actions designed to guarantee the right of persons with albinism to the highest attainable standard of health are incorporated into existing health projects and programmes of general scope and that, in addition, specific programmes are designed and given priority.**